Introduction

Case management has existed since the nineteenth century, but has received more attention in the past quarter century. The concept of case management first emerged in the early 1900s within the context of the disciplines of nursing and social work. In the early 1970s, case management was formally introduced by the U.S. Department of Health, Education, and Welfare.

Early HIV/AIDS case management was concerned primarily with coordinating support services for a terminally ill population, essentially providing support to assist people with AIDS and their families as they coped with a disease that ultimately resulted in death. Some levels of nursing case management and medical case management were beginning to emerge even during the early years of the epidemic, but the primary focus of case management was coordinating and obtaining psychosocial support services.

Beginning in 1991, the Ryan White CARE Act supported HIV/AIDS case management as a core component to the delivery of HIV services, and in fact, mandates case management in rural communities under Title II. The Ryan White CARE Act became the primary funder for support services (i.e., transportation, housing, food, support groups, mental health counseling, etc) and case management was seen as the link between Community Based Organizations (CBOs) and Local Health Departments to provide not only case management, but the wide range of wrap-around services from single locations.

Changes in the epidemic have forced communities across the United States to examine the models they use to deliver HIV/AIDS services in their local communities. The new treatments (and their current success) require a much stronger link between provision of medical care and the wrap-around services. The demographic of the infected populations are changing, requiring new expertise in dealing with multiculturalism, the issues of women, children and youth, issues of substance abuse and mental illness and all the attendant problems of populations living within poverty. More and more, models of case management need to expand to incorporate the principles of chronic disease management.

Case Management Standards

These standards are intended to provide a direction to the practice of HIV/AIDS case management in the state of Idaho. They are also intended to provide a framework for evaluating the practice of HIV/AIDS case management and to define the professional case manager's accountability to the public and to the client to whom the profession is responsible.

Case Manager Education Requirements and Training

As the "front line" in providing vital service linkages for people living with HIV disease and AIDS, case managers must be adequately and appropriately experienced and trained. Case management service will be provided by a qualified case manager. A case manager must have a bachelor's degree or extensive experience (specialized case management training and 1-2 years experience) in a human services related field, such as social work, psychology, nursing, or health education.

Definition of HIV/AIDS Case Management

Case management is a range of client-centered services that links clients with health care, psychosocial and other services to ensure timely, coordinated access to medically appropriate levels of health and support services, continuity of care, ongoing assessment of the client's needs and personal support systems that prevent unnecessary hospitalization or that expedite discharge, as medically appropriate from inpatient facilities.

Case management serves as a means for achieving client wellness and autonomy through advocacy, communication, education, identification of service resources and service facilitation. Case management is a multi-step process which ensures coordination of medical and specialty care and access to a range of appropriate medical, psychosocial, and social services for the client. Case management assesses the needs of the client, arranges, coordinates, monitors, evaluates, and advocates for a package of multiple services to meet the specific needs of the clients.

Client-Centered Approach in Case Management

The client-centered model was originally developed by Carl Rogers and contains the key ingredients of a helping relationship: empathy, respect, and genuineness. The fundamental tenet of this approach is that all people have an inherent tendency to strive toward growth, self-actualization, and self-direction. A client-centered approach places the needs, values, and priorities of the client as the central core around which all interaction and activity revolve. Understanding how the client perceives their needs, their resources, and their priorities for utilizing services to meet their needs is essential if the case management relationship is truly going to be client-centered.

Each client has the right to personal choice though these choices may conflict with reason, practicality, or the case manager's professional judgment. The issue of valuing a client's right to personal choice is a relatively simple matter when the case manager's and client's priorities are compatible. It is when there is a difference between the priorities of the case manager and their client that the case manager must make a diligent effort to distinguish between their own

values and judgments and those of their client. One of the most difficult challenges for a case manager is to see their client making a choice that will probably result in negative outcomes, and which opposes the case manager's best counsel. In these situations, we must be willing to let the client experience the consequences of their choices, and hope that the relationship with the case manager will be a place to which the client can return for support without being judged.

It is the case manager's responsibility to: offer accurate information to their client; assist their client in understanding the implications of the issues facing them, and of the possible outcomes and consequences of decisions; present options to the client from which they may select a course of action or inaction; offer opinion and direction when it is asked for, or when to withhold it would place the client or someone else at risk for harm; and be available to support and problem solve.

The role of the case manager is to work with clients to help them live as independently as possible, involving the client in the case management process. Case managers serve as advocates to ensure that clients have access to appropriate medical, social, vocational, and educational services.

Case Management Objectives

Case management objectives are: to provide a comprehensive client-centered assessment of medical, social, and psychosocial needs; to develop a client-centered service plan which addresses clinical care, social and psychosocial needs; to provide documented assistance in coordinating multidisciplinary health care services and referral activities in order to minimize duplication of services; to provide on-going follow-up activities to ensure delivery of needed health care and social services; to maximize the quality of life for clients by providing emotional support to the client; and to provide annual reassessment and evaluation of client needs and case management activities.

Case management activities may also include: screening for eligibility for entitlements, assistance with completing applications for entitlements, referral to special benefit programs for individuals living with HIV; advocating and negotiating on behalf of the client to secure needed entitlements; referring the client to community-based organizations which provide needed services such as support groups, food pantries, etc.; providing crisis intervention services, including referrals for emergency services such as food, clothing, or shelter; arranging for home care services which supports the client's ability to remain at home; arranging transportation to and from medical related appointments; assisting clients in arranging for advanced directives in health care; and maintaining a system for tracking clients to ensure that they are not lost to follow-up.

Allowable Services

In the Idaho legislative session 2003, the Idaho Legislature approved Rules Governing Human Immunodeficiency Virus (HIV) Related Services which will guide in provision of case management services in Idaho (see Rules in Appendix A). According to the rules, the following services many be provided to eligible clients:

Ambulatory outpatient medical care: ambulatory outpatient medical care to include provision of professional diagnostic and therapeutic services related to HIV provided by a physician, physician's assistant, clinical nurse specialist, or nurse practitioner in an outpatient community based setting.

Case management service: case management service provided by a qualified case manager. A case manager must have a bachelor's degree or extensive experience in a human services related field such as social work, psychology, nursing, counseling, or health education. The services will include:

- an assessment of the participant's needs and personal support systems;
- development of an individual service plan;
- coordination of services identified in the individual's service plan;
- monitoring services received; and
- re-evaluation of the participant's service plan periodically to make revisions to reflect the individual's needs.

Dental care service: dental care service includes diagnostic, prophylactic, and therapeutic services related to HIV provided by dentists, dental hygienists, and similar professional practitioners.

Drug reimbursement service: drug reimbursement includes ongoing service to pay for approved pharmaceutical medications related to HIV. This service includes ADAP and locally administered reimbursement programs.

Health insurance service: health insurance includes a program of financial assistance to maintain a continuity of health insurance or to receive medical benefits that covers HIV related services. Financial assistance for health insurance must be proven to be cost effective.

Mental health service: mental health therapy and counseling to an individual with a diagnosed mental illness includes psychological and psychiatric treatment and counseling services, including individual and group counseling. The service must be provided by a mental health professional employed by or under contract with the Department's Mental Health Program.

Nutritional service: nutritional services includes the provision of nutrition education and counseling. Nutritional supplements will also be covered if prescribed by a physician.

Psychosocial support services: psychosocial support services includes peer counseling, support group services, caregiver support, bereavement counseling, drop-in counseling, and education provided to a participant focused on HIV related problems. These services will be provided by licensed counselors or licensed social workers.

Substance abuse service: substance abuse treatment and counseling includes the provision of treatment to address substance abuse problems provided in an outpatient or residential health service setting under contract with the Department's Substance Abuse Program.

Transportation service: transportation includes conveyance services provided to an individual in order to access HIV related services.

INTAKE

Intake

The initial interview provides the case manager with important first impressions about the client and their needs. The first contact between the client and the case manager also establishes the basis for development of rapport and trust, which are essential elements of successful case management. The intake interview is a screening process, not a comprehensive assessment of psychosocial problems, needs, and resources. It also serves as the primary source of demographic information gathering.

Enrollment into a case management program is often the client's first encounter with the HIV services system. The "Authorization to Coordinate Services" should be obtained at this time. As part of the enrollment into the case management program, clients are informed of their right to confidentiality and the legal limitations placed on the case manager. Case managers must ensure that HIPAA's rules and regulations are followed regarding the client's right to privacy and confidentiality when information is released to others. All information about a client and the client's family that is obtained by the case manager in carrying out case management tasks shall be held in the strictest confidence; clients will be informed that information may be released to the STD/AIDS Program if the client is receiving services through Ryan White Title II funding; information may be released to other professionals and agencies only with the written permission of the client or his or her guardian; this release shall detail what information is to be disclosed, to whom, and in what time frame; and inform the client of certain confidentiality limitations (threats of suicide or harm to others).

It is important not to assume that anyone—even a client's partner or family member—knows that the client is HIV positive. Part of this discussion should include inquiry about how the individual prefers to be contacted (at home, work, by mail, code word on the telephone, etc.). Case managers should identify themselves only by name, never giving an organizational affiliation that would imply that an individual is sick or receiving social services.

Another element of the enrollment process is the "Authorization to Release Information" in which a client authorizes in writing the disclosure of certain information about his/her case to another party (including family members). Included in the form are the purpose of the disclosure, the types of information to be disclosed, entities to disclose to and the expiration date of client authorization. Part of the discussion should include information about the intent of the release of information, its components, and ways the client can nullify it.

An additional document presented to the client is the "Client's Rights and Responsibilities." The case manager reviews all of the rights and discusses the responsibilities as part of the overall discussion of a client's participation in the

case management system. A signed copy (by the client) of the client's rights and responsibilities should remain in the client's file and a copy should be given to the client to keep.

The client will be provided with a clear explanation of the range of services offered by the case management program and of the role of the case manager. Questions that the client or his/her support persons might have about the program and about how involved the case manager will be with the client may arise at this time. It is important for the case manager to make the client aware of the limitations of the program as well as its offerings. This information must be provided during the intake in order to avoid problems that inappropriate expectations can cause the client and the agency later on.

Verification of eligibility: Client self-report of HIV status is documented at intake. Acceptable verification includes at least one of the following: a copy of the client's seropositive test results from the test provider; a signed document from a physician or his/her designee, verifying that the client is HIV positive; lab results at any time during the client's lifetime that show the presence of the human immunodeficiency virus; or written verification from another case manager or provider who has one of the above documents in the client's file.

Process

1. Intake is initiated by a prospective client, his or her representative, or by a third party referral (verified at least verbally by client) to the case management agency.
2. The case manager will screen the service request/referral for basic admission criteria and assess the need for immediate intervention.
3. An Intake form will be completed and the prospective client is informed of agency services and limitations.
4. The case manager conducting the intake will provide the prospective client with a description of the services available from the agency, as well as services available from other agencies, based on need.

ASSESSMENT

Assessment

An assessment is an information gathering process which includes a face-to-face interview between a client and case manager and acquisition of secondary data from health and human services professionals and other individuals. It is a cooperative and interactive process during which a client and case manager collect, synthesize, and prioritize information which identifies client needs, resources, and strengths, for purposes of developing a service plan. Accurate assessment of the client is well documented as a critically important step in the case management process, identifying both the client's needs and strengths.

Five major points to take into consideration when beginning an assessment:

- involvement of the client is absolutely essential
  - it is tempting to formulate in your own mind what you think the client's problems really are, however, these formulations may differ radically from what the client sees as the problems
- assessment always involves making judgments
  - people, their lives, and their situations are complicated entities. You, along with the client, need to make decisions regarding what appears to be relevant and what does not, prioritizing what is the most important to pursue
- attending to a client's strengths provides you with an already available means of finding solutions
- a single, clear definition of the problem may not exist
  - it is up to you as the case manager to identify, define, and prioritize problems
- assessment needs to be an "ongoing process"
  - problems, strengths, and issues can change over time
  - service plans must be adjusted to reflect current and on-going needs

The process of identifying client needs and strengths should be a participatory activity that involves client self-assessment and supports client self-determination. Equally important is ongoing collaboration between the case manager and other health and human service providers and individuals involved with the client. Case conferencing and consultation with other agencies providing services to the client should be an ongoing activity of case management and appropriate documentation of these activities should be included in a consistent way in the client's file.

Elements of the assessment include: health provider information; basic needs assessment (education, employment, financial); living arrangements; children/dependents; social support; medical information; mental health information; substance use information; legal information; independent living

skills; HIV background and prevention education information; and drug adherence information.

SERVICE PLAN DEVELOPMENT

Service Plan Development

For the most efficient use of time and for effective outcomes to occur, there must be a clear plan that directs the activities of the client and the case manager. This plan becomes the basis for evaluating what services were provided and whether they achieved the desired outcomes. Once the case manager has gathered sufficient information from the intake and assessment, it should naturally follow that this information will form the basis of the service plan. A service plan documenting services to be provided must be developed and updated on an ongoing basis in order for services to be eligible for reimbursement through Ryan White Title II.

The major components of the service plan include: identification of agreed upon priority client needs and goals; identification of barriers; quantifiable objectives with specified action steps; designated individual/s who will perform the activity; time line for each step; and client and case manager signatures and date. The service plan provides the basis from which the case manager and the client work together, as partners, to access the resources and services which will enhance the client's quality of life and his/her ability to cope with the complexity of living with HIV disease. The client and other members of their support system play a vital role in the process of developing the service plan. This utilizes the inherent supports the client brings to the case management relationship. The process supports client self-determination whenever possible and empowers a client to actively participate in the planning and delivery of services.

When setting up a service plan, it is necessary to come to an agreement about what tasks will be done by the case manager and what the client will do. Most clients will count on the case manager to guide them through the maze of the health and human services system, and to present options and help them develop contingency plans, should the initial efforts fail to produce the desired results. It is important to set up a time frame within which progress toward the goals will be jointly assessed and the revisions of the plan can be made.

The role of the case manager is primarily one of resource coordination. When, during the service plan development, specific knowledge or skills are needed beyond those of the case manager, consultation with other professionals is sought with appropriate releases of information.

Tasks in Implementing the Plan

1. Service referral/brokerage/linkage includes: making referrals; reducing barriers/facilitation access; referral follow-up; advocating with referral agencies when needed; and emotional support.

2. The case manager and client will work together to decide what actions are necessary to accomplish each objective and who will take responsibility for each task. The case manager will encourage and support clients to act on their own behalf whenever possible.
3. Referral is the act of directing a person to a service, in person or through telephone, written, or other type of communication. Referrals to outside agencies for specified services are often needed in order to meet the service plan objectives. Referral agencies should be assessed for appropriateness to client situation, lifestyle, and need. The referral process should include timely follow-up of all referrals to ensure that services are being received. Agency eligibility requirements should be considered as part of the referral process. Any referral made should be appropriately documented in the client record.
4. Monitoring the progress of the service plan: Follow-up and implementation are inseparable. It is through systematic follow-up that the case manager and client discover whether the plan is working and when it needs revision. The service plan should be regularly reviewed to determine whether any changes in the client's situation warrant a change in the plan and also to determine whether the goals and objectives of the plan are being met in a timely manner and, if not, why not. Each agency providing case management should incorporate service plan review in their Quality Assurance (QA) protocol. Additionally, monitoring client satisfaction is an ongoing process throughout the delivery of case management services. It determines whether the mutually agreed upon goals of the service plan are truly meeting the needs of the client. At any point, this process may trigger a need for re-evaluation of the plan and/or the process the client and case manager have established working together. The agency QA protocol should include a process for formally assessing client satisfaction, which could include written surveys, focus groups, or other appropriate methods.
5. Advocacy is the act of assisting someone in obtaining needed goods, services, or benefits (such as medical, social, community, legal, financial, and other needed services), especially when the individual has had difficulty obtaining them on his/her own. Advocacy does not involve coordination and follow-up on medical treatments. Whenever possible, advocacy should build upon, rather than fragment, agency cooperation and collaboration.

Process for Implementing the Plan

1. According to ADAPA 16, Title 02, Chapter 05, Rules Governing Human Immunodeficiency Virus (HIV) Related Services, a service plan must be developed and must document services to be provided.
2. Case conferences and other forms of care coordination can help ensure that all providers involved in a client's care and treatment work together to achieve the best mix of services and avoid duplication.
3. Successful implementation of the plan may require the case manager to take a more active role in helping the client identify problems, which the client may not necessarily see, that could impact the client's ability to fulfill his or her obligations to the service plan.
4. The service plan should be used as an important tool for helping the client escape a crisis mode of coping with his or her problems and service needs. With proper support many clients are able to increase their coping skills and stabilize their life situation to avoid the cycle of moving from one crisis to another.

Documenting Implementation

Implementation of the service plan includes careful documentation in the progress notes of each encounter with the client, persons in his or her support system, and other providers involved with the client's care. Date of contact, information on who initiated contact, and any action that resulted from the contact should be included in the documentation. All documentation should be signed and dated by the case manager.

SERVICE PLAN FOLLOW-UP AND MONITORING

Service Plan Follow-up and Monitoring

Monitoring is an ongoing process that involves collection and analysis of data and information that results in: evaluation of the effectiveness and relevance of the service plan; evaluation of the level of client satisfaction; measurement of client progress toward stated goals and objectives; and determination of the need for service plan revision.

The overall goals of follow-up and monitoring are to: ensure the service plan is being implemented and is adequate to meet client service needs; make sure the care and treatment the client receives from different providers are being coordinated to avoid needless duplication of or gaps in services; ensure any changes that have emerged in the client's condition or circumstances are being adequately addressed in order to avoid crisis situations; and maintain client and case manager contact on a regular basis to build trust, communication and rapport between them.

Clients should be encouraged to contact the case manager when changes occur in their health condition, in social factors that impact their day-to-day living, or in their practical support systems. Careful planning by the client and the case manager can determine how often contact is needed to minimize crisis situations and to best meet the client's anticipated needs. Follow-up and monitoring activities can occur through direct contact (face to face meetings or telephone communication) with the client. Client contact with the case manager often occurs on an ad hoc or drop-in basis. Follow-up can occur in the case manager's office, at the client's home or temporary residence, in the hospital, or at other sites in the community.

Indirect contact with the client, client's family or caregiver, primary medical provider, service providers, and other professionals also provides follow-up and monitoring information. This can happen through meetings, telephone contact, written reports and letters, review of client records, and through client and/or agency staffing.

To build an effective client-centered relationship, it is important that at least some of the follow-up and monitoring happened in face-to-face meetings with the client. This allows the case manager to offer emotional support to the client and assess the client's overall affect and general physical condition.

REASSESSMENT

Reassessment

Clients are reassessed to identify unresolved and or emerging needs, guide appropriate revisions in the service plan and inform decisions regarding discharge from case management services and/or transition to other appropriate services. Reassessment is conducted in the event of significant changes in the client's life or on an annual basis.

Reassessment is conducted by the case manager and is performed according to established standards and criteria. The process of reassessment should encourage active participation by the client and/or significant others. The process of reassessment may involve the collaboration between case manager and other health and human service providers, individuals actively involved with the client, and through client record review.

Documentation required includes: updated demographic data; updated assessment data acquired from health care providers and other professionals and sources; and updated service plan reflecting both updated demographics and assessment data.

TRANSFER AND DISCHARGE

Transfer and Discharge

A systematic process shall be in place to guide transfer of the client to another program or case manager, and/or discharge from case management services. This process includes clear documentation of the reason/s for discharge, notifying the client of case closure and the appeals process.

Conditions under which transfer/discharge shall occur: death of the client; the client and/or client's legal guardian requests that the case be closed; client makes fraudulent claims about their HIV diagnosis or falsifies documentation; or client enters prison.

Conditions under which transfer/discharge may occur: client is "lost to follow-up;" client moves into a system of care which provides in-house case management; client moves out of the case manager's geographic service area; client becomes self sufficient; client is unwilling to participate in service plan; client exhibits a pattern of abuse of agency staff, property, or services; or client needs are more appropriately addressed in other programs.

The process for transferring or discharging a client will be discussed with the client and options for other service provision will be explored and documented.

In instances where the case management agency initiates termination, the case manager should consult with supervisor about their intent to discharge client; the client is informed of intent to discharge and is provided with information regarding appeal of that decision; the client is informed of other community resources available that may be able to meet their needs; and in some circumstances, a client may be suspended from services for a specified period of time (every effort should be made to assist the client in being successful in meeting expected program guidelines and becoming re-eligible for services); and a discharge summary is prepared, which will include careful documentation of reason/s for discharge and a service transition plan as appropriate.

DEFINITIONS

Definitions

Adherence (Treatment Regimen): following the recommended course of treatment by taking all prescribed medications for the entire course of treatment, keeping medical appointments and obtaining lab tests when ordered.

Case managers can help clients identify and remove barriers that prevent them from taking medications properly and with a high degree of consistency. Maximizing the effectiveness of treatment is dependent upon identifying all of the elements in a client's life which affect their ability to follow the recommended course of treatment. This assessment should include six areas of client functioning: client education; motivation; self-efficacy; barriers to performance; remembering; and side effects.

Advocacy: is the act of assisting someone in obtaining needed goods, services, or benefits (such as medical, social, community, legal, financial, and other needed services), especially when the individual has had difficulty obtaining them on his/her own. Advocacy does not involve coordination and follow-up on medical treatments. Whenever possible, advocacy should build upon, rather than fragment agency cooperation and collaboration.

Americans with Disabilities Act (ADA): is a civil rights law passed by Congress in July of 1990 to protect people with disabilities from discrimination in public and private services and accommodations. Since HIV disease is considered a disability, the ADA protections apply to persons living with HIV/AIDS.

Biopsychosocial: a comprehensive picture of a person containing information about her/his physical (bio), psychosocial and social health.

Broker: to act as an intermediary or negotiate on behalf of a client.

Service Plan: a written plan that directs the activities of the client and the case manager. The service plan delineates the case management goals and objectives required to coordinate and link the client to the continuum of health and support services required to manage their disease.

Client Record: a collection of printed and/or computerized information regarding a person using services currently or in the recent past.

Confidentiality: the process of keeping private information private. Information given by a client to a service provider will be protected and will not be released to a third party without the explicit written permission of the client or his/her representative. Information may be released only in the following circumstances:

when a written release of information is signed by the client; when there is a clear medical emergency; when there is a clear and imminent danger to the client, case manager, or others; when there is possible child abuse; or when ordered by a court of law.

Cultural Competency: refers to whether service providers and others can accommodate language, values, beliefs, and behaviors of individuals and groups they serve.

Demographic Information: descriptive information which may include, but is not limited to age, race/ethnicity, and gender. This information provides a profile of people receiving services from a specific agency.

Emotional Support: the ability of the case manager to listen and empathize is the essence of emotional support in the case management relationship. In cultivating a trusting relationship, it is important for the case manager to strike a balance between the empathetic role, utilizing active listening skills, developing rapport, and providing emotional support—and the objective role which requires engaging and encouraging the client toward concrete actions to achieve a desired outcome. Because case management is often defined as a task-oriented process, we tend to focus on the "doing" of tasks with the client, and forget the importance of "being present." Being truly available to offer emotional support is particularly important in situations where we do not have resources to meet the needs that clients present with.

Grievance: a verbal or written complaint or concern regarding a practice or policy of an individual or organization per the organization's policy.

Quality Assurance/Improvement: a method of program/service evaluation, which is designed to assure, as best possible, that the highest quality of services is provided to the client.

Ryan White CARE Act: passed by Congress in 1990, the purpose of this federal Act is to provide emergency assistance to communities that are most affected by the HIV epidemic and to make financial assistance available to state and other public or private nonprofit entities. This assistance provides for the development, organization, coordination and operation of more effective and cost efficient systems for delivery of essential services to individuals and families with HIV disease.